



Intellectual & Developmental Disabilities Task Force

NOTICE OF MEETING AND AGENDA

The Intellectual & Developmental Disabilities Task Force met on Wednesday, June 27, 2018 at 10:00 a.m. (CDT), at the Porter County Community Foundation, 1401 Calumet Avenue, Valparaiso, Indiana, 46383.

Task Force Members Present: Lt. Governor Suzanne Crouch, Sara Renner, Jesse Wyatt, Joe Langerak, Kim Milas, Kevin Moore, David Reed, Joshua Bougie, Steve Cook, Shawn Fulton, Rebecca Kasper, Kylee Hope, Dana Long, Julie Reynolds, Kim Dodson, Jason Meyer, Christine Dahlberg, Jonathan Burlison, Kathleen McAllen.

Absent: Trent Fox (Laura Chavez attended in his place), Debbie Pierson (Sara Renner and Jesse Wyatt attended in her place), Terry J. Stigdon (David Reed attended in her place), Betty Williams (Shawn Fulton attended in her place), Dr. Pam Wright (Dana Long attended in her place), Allison Taylor (Joshua Bougie attended in her place).

- I. Lt. Governor Suzanne Crouch calls meeting to order (10:00 a.m.)
 - a. Introduction of Task Force Members
 - b. Lt. Governor Crouch introduces State Senator Ed Charbonneau
- II. Listening Session – Facilitated by Ellen DeMartinis, CEO Opportunity Enterprises (10:05 a.m. – 10:55 a.m.)

Donna Belusar, President & CEO of ADEC. Donna is here today representing individuals working at ADEC industries and gives public comment on their behalf.

Toby Weirich, a nationally certified guardian for over 20 years. Here today representing Lisa who is 41 FSW. Lisa wants people to know that she made a choice to be at ADEC's sheltered workshop. She is improving and dreams to have a community job and a career in housekeeping.

Diane Stevens, physical therapist working with all ages and types of disabilities. One of the biggest issues is from Anthem's Medicaid program has denied items that are necessary to the advancement of individuals to achieve independence. She asks Task Force to have medical reviewers ask why the individuals need the equipment requested instead of denying.

Kathy Jackson, Chief Human Resources at Opportunity Enterprises. Kathy has worked in the past at a major retailer and compares the costs to hire and train individuals. It costs \$4,000 to onboard someone at Opportunity Enterprises and in retail it costs approx. \$500. If this continues, organizations will be unable to continue to serve clients.

Susan Elsworth, Director of NOFAS and parent of foster children who have Fetal Alcohol Syndrome Disorder (FASD). There are challenges for children because people don't understand the syndrome. Please consider what it takes for these complex needs.

Latosha Knight, Director of Day Service Program at Opportunity Enterprises. There is concern for community integration requirement for day programs. This presents challenges for staff because often times there is limited capacity for those providers who serve a large number of individuals. This is especially challenging in rural areas.

Max Danko, Employee of Secure Shred at Opportunity Enterprises. Max shared how much he enjoys his work and shares some experiences he's had in the sheltered workshop since he was hired in 2016 including special recognition he's received, "Business Service Client of the Year."

Donna Elbrecht, President and CEO of EasterSeals ARC in Ft. Wayne. Donna shared support for Pre-Employment Transition Services. It requires VR to set aside federal funds to provide services for students with disabilities. She encourages the Task Force to look at ways through more funding to be creative and more innovative beyond the 5 basic Pre-ETS services.

Phillip Hathaway, a former VR client. Comments on VR Order of Selection and shared his personal success story of working in Information Technology. He has a career that he loves. Without VR helping him to get his start he wouldn't be where he is today. He wants to ensure that people like him are given the same opportunities to succeed.

Kevin Steele, Board member at Opportunity Enterprises. Kevin emphasized the importance of allowing service providers to own and maintain residences for their clients. Finding suitable living is a challenge, especially in rural areas. By directing that all clients live in housing owned by a third party, you are taking away client choice.

Mark Ruiz, Father of a son with Down Syndrome and Opportunity Enterprises Board member. As his son grew and matured, he needed more supports. His wife/Ethan's mother felt as though various therapies he needed weren't available and benefits packages didn't provide what they needed. Listen to the moms – the moms know what these kids need. Make benefit packages more flexible to get what works best for their child.

Tiffany McCammon, Intake Coordinator for Opportunity Enterprises. There is a continued need for day programs and facility based work options. Community employment is not always the preferred option –please let the individual voices be heard when they tell us what they want.

Jennifer Lantz, Executive Director of IMPG. They are a case management company that supports well over 13,000 individuals. It is critical to provide appropriate services to individuals in need. For case managers to have the time, appropriate rates are needed. She asks that the Task Force review and update the policy guidelines around RFA services that include: home, environmental and vehicle modifications. More flexibility is needed for the FSW waiver.

Laurie Moulton, parent and Board Member at Opportunity Enterprises. Her son David will be 40 years old and has Down Syndrome. He lives at home and is mostly self-sufficient. She wants to address the importance of the facility based employment/sheltered workshops. He feels safe and supported and thrives in this community. She doesn't worry that he will be taken advantage of. Community employers are not able nor are they interested in provided for his basic needs – and can't provide the amount of supports that he needs.

Lisa Barrios, Director of Daily Living Skills at Opportunity Enterprises. Daily Living Skills is a program that serves the severe and profoundly disabled who require mostly one on one assistance. The current CIH waiver provides help only in extreme circumstances and expects that parents are their caregivers up until they are 80 years old. Please consider changing this.

Kathy Savich, Director of Community of Opportunity Enterprises. Comments were regarding negative impact of VR Order of Selection and staffing crisis.

Pam White, Assistive Technology professional with Opportunity Enterprises. Comments were regarding Assistive Technology, VR, Order of Selection and the negative impact on individuals.

Julia Young, a Resident of Porter County, former special educator, and also an individual with an acquired disability. VR Homemaker job goal is what allowed her to adapt to her environment as her eyesight has deteriorated.

Don Wierenga, Director of Operations at Corvillia. Don's comments were around the topic of freedom of choice. Individuals have the right to choose where they live.

Loren Pilcher, Director of Supported Living at Rauch in New Albany. The comment was on the topic of DSP staffing crisis. He has to turn people away weekly because they can't serve them. Architects needs builders to create the inclusive society that they want and the Task Force is that architect.

Tammy Blackmon, mother. Her 28 year old son is employed at Opportunity Enterprises. Her comments were in support of the Job Source program at Opportunity Enterprises and around the low wages paid to DSPs.

Lisa Danko, mother is Max Danko who spoke earlier. Her comments were in support of the Opportunity Enterprises workshop.

Rick Amrhein, Parent of a child with a disability and on the board of Opportunity Enterprises. His comments were around habilitation services and the current rate structure that isn't working well. There are other models that can be used that will ensure that agencies can maintain quality offerings to all who can use them.

Shelia Janik, Mother of son, Ben Bray who is 40 years old. They both depend on Opportunity Enterprises for work and social activities. She is a registered nurse in the intensive care unit and we're saving babies at earlier and earlier ages. Because of this please consider expanding services.

Randy Hall, CEO Cardinal Services. Comments were around group homes and community living settings and the challenges that come with staffing and opportunities for those living there. There are challenges around ensuring consumer choice.

Mary Joe Nuland. Comments were around the need for affordable healthcare and housing.

Sharon Sanders Maher and her daughter Kristin Nichole. Comments were around choice and opportunities for her daughter at Opportunities Enterprises and her negative experience with VR.

Jennifer Fryer, Innovations in Learning. Comments were around ensuring that individuals have a voice.

Cynthia Grass Black, parent and guardian. Comments were in support of the sheltered workshop environment.

Linda Johnson, a professional in the field with over 30 years of experience. Linda's comments were focused around choice for the individual who has a disability.

III. Review and Approval of Minutes from April 18, 2018 Meeting

There was a motion to approve the minutes and a second motion to approve. The minutes were approved.

IV. Review of Draft Report (*30 Minutes*)

a. Review and discuss Goals

Goal #1 – Kim Dodson suggests the word “typical” be removed.

b. Vote on Goals – Motion to approve the Goals and second. Goals were approved.

****Lt. Governor Crouch** makes special introduction of State Senator Ed. Charbonneau and he gives brief remarks (off microphone).

Goal of Today's Meeting: **To find the best options for Hoosiers with Intellectual and Developmental Disabilities to live as independently as possible.**

V. Array of Residential Options – Julie Reynolds, Director of Strategic Initiatives, DDRS, and Task Force Member (*25 minutes*)

a. Current Residential Supports.

Julie Reynolds gave overview of the different kinds of residential options for individuals with disabilities in Indiana.

b. Assisting individuals' transition from institutional care.

Julie Reynolds gave a detailed breakdown of where individuals are living in nursing facilities around the state. The lower the age and length of stay is a key factor in the likelihood of getting transferred out of the nursing facility.

Kylee Hope commented that there is a need to direct attention to the children who are in nursing facilities. These children should be looked at individually and one should look at duration of stay and the demographics to determine if they can go on the CIH waiver or go into an extensive medical needs home if appropriate. Purpose is for short term acute stays to address specific needs.

Individuals in nursing facilities is a priority category on CIH waiver. DDRS is also partnering with the ARC and self-advocates to work in nursing facilities to target individuals and help them understand what their life is going to be like when they transition.

VI. Expanding affordable and accessible housing with supports

a. Options included in Indiana Housing and Community Development Authority (IHCDA) QAP – Kylee Hope, Director, DDRS, Task Force Member *(10 minutes)*

The Lt. Governor is submitting written information to the Task Force. Currently, the IHCDA administers the low income housing tax credit program for the State of Indiana. It allocates federal tax credits to affordable housing developers. The credits are then sold to investors to generate equity that the developer uses to build the housing. The IHCDA is required to create a Qualified Allocation Plan (QAP) to outline the manner that it will use to allocate the tax credits. In the 2018-19 fiscal year, the IHCDA QAP included a new set aside called Community Integration. Through this set aside, the IHCDA reserves 10% of its annual tax credits for developments that will provide integrated, affordable housing for persons with intellectual and developmental disabilities. Twenty 20 -25% of the units in the eligible development must be designated for occupancy by a household in which at least one member has an individual with an ID/DD. The units must be scattered throughout the property and flow – this means that they cannot be segregated in certain areas or certain floors. The developers must identify a local disability organization or a non-profit service provider to help refer clients to the units and to help connect the residents with services in the community. Providing those services is part of the total package. In 2018, the tax credit awards were approved by the board members. Awards were made to three developments that met the Community Integration 10% definition as identified. 125 affordable housing units will be built and 28 dedicated targeted to persons with ID/DD. They are located in Tippecanoe county, Ft. Wayne (Allen County) and Columbia City. In 2019, they are projecting 4-5 developments and are partnering with FSSA to do a best practices training session with stakeholders in the spring to better educate them. IHCDA taking a step in the right direction. Kylee Hope added that she appreciates the IHCDA that is an agency outside of the disability world to recognize a need in the disability world.

In April, HUD released notice that \$100 million is available and IHCDA has formally applied for \$5 million (997 houses could be served with this) with Housing and Urban Development Authority for new funding. Awards will be made in August by HUD.

Technology options available presented by Kylee Hope:

Technology. Technology promotes independence and self-reliance and even builds skills. It adds privacy for individuals, improves the quality of life, creates access and is one way to address the workforce shortage. Kylee read a portion of the Executive Order from Ohio and she will provide an executive summary of this topic. DDRS is looking for ways to promote the utilization of technology. It is an area where they need to expand technology utilization. Some areas to explore: Adaptive aids, A.I. smart home technology, etc.

- b. Jason Meyer, President & CEO Passages, Inc., Task Force Member *(10 minutes)*
Jason also has a role as CEO of Whitley Crossing's Neighborhood Corporation. It is an affordable housing corporation that was started in 1999. Jason gave an overview of the housing communities that were created because of the lack of affordable and accessible housing allowing individuals to age in place.

Jason covered the different types of funding to create opportunities? The Lt. Governor asked about the need: is the need greater than the demand? Jason answered that yes, the need is great for affordable and accessible housing. Challenges are for the over income to qualify for low income housing – suggested one recommendation is giving an exemption to ID/DD individuals.

- c. John Niederman, President, Pathfinder Services *(10 minutes)*
People with ID/DD eligibility and determination for SSI/SSDI for Medicaid and eligible for support services are extremely low income. There is a considerable shortage of affordable housing in Indiana. Depending upon which funding source you use, there are different eligibility requirements. He advocates bringing low income and disability services together. Developers with the service providers.
- d. Andy Rosentahl & Len Grabovsky, Terebinth Group, LLC *(10 minutes)*
Andy and Len presented on supported housing that they provide for the IDD Community.
- e. Ken Smith, Director of Development, Rest Assured Overview of Remote Support
Ken provided an overview of the Rest Assured electronic monitoring system.

VII. Shared Living White Paper (Jonathan Burlison, CEO, Bridges, Task Force Member *(15 minutes)*)

Jonathan presented his white paper to the Task Force.

Kylee Hope encouraged the Task Force to consider when developing and planning for options for living in Indiana for the next 10 years, that it is person centered and around what the individual would like and not shared living model that currently exists. IX. Tying Funding to Individuals White Paper – Jonathan Burlison, CEO, Bridges, Task Force Member *(15 minutes)* **NOTE: Jonathan presented his White Paper directly after his first White Paper was presented.

Jonathan presented to the Task Force on importance of control and choice to individuals. The waiver setting allows flexibility and gives more control to individuals as compared to when funding is tied to providers/beds. Task Force should consider what funding is tied to providers and what is appropriate for individuals who should have freedom of choice.

INARF doesn't agree with a mandatory elimination of group homes. They prefer NOT to take options off the table. Nearly 25% of the individuals living in group homes are 60 years old and older.

The ARC supports choice for individuals on when and where they receive services. Families prefer waiver homes and don't understand until they want to part ways from

provider and move between the two. All should be considered as new residential models are considered.

Kylee Hope discussed ICF/IDDs and making sure we have appropriate services for the individuals so that they eventually could transition to HCBS waiver. Ensuring the right services are available to ensure the best life possible is important. There are safety issues and access to high skilled service providers who have safety, medical and behavioral needs. Agrees that we should know what the inventory is and what's available.

VIII. Community Living Expansion Initiative White Paper – Steve Cook, President/CEO, INARF/Ability Indiana, Task Force Member (15 minutes)

Steve presented his white paper to the Task Force.

Kylee commented and encouraged Task Force to thoroughly consider priority categories in general and that currently, it is crisis oriented. Task Force should consider the demographics entering the system and understand the purpose of these waivers is for the provision of Home and Community Based services in the community. They might consider the redesign of the type of waiver, or the type of funding that is tied to those waivers and the types of supports that are currently provided. How can we ensure individuals can access the supports they need? Kim Dodson agreed and asks that the White Paper focus more upon the need of the individual.

Julie Reynolds commented that paid services in Indiana account for 25% of the individuals who have ID/DD are being served. The other 75% are receiving supports somewhere else. Task Force should remember that this is a broad look at what is needed and not thinking that services will take care of all of the needs.

X. Task Force Discussion

- a. Ideas/recommendations (other than White Paper topics) based on today's Listening Session or Presentations that Task Force Members think should be explored?

The Lt. Governor asked Kylee Hope to do a white paper on the Community Mental Health Centers will not see individuals with ID/DD and how to improve on this.

- b. Are there unmet residential needs the Task Force has not discussed?

XI. Next Meeting – Wednesday, July 18, 2018, 11:00 am ET

Indiana Government Center South
402 W. Washington Street
Indianapolis, IN 46204

XII. Meeting adjourned